GOALS AND RECOMMENDATIONS FOR A STATEWIDE HEALTHCARE INFORMATION EXCHANGE

A Report from the Indiana State Medical Informatics Commission

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Medical Informatics Commission Report and Recommendations

Introduction

Senate Bill 566, (SB 566), established the Medical Informatics Commission (MIC) and the scope of work to be accomplished through the Commission. The legislation asks the Commission to, "establish a plan for the creation of an interoperable, statewide healthcare information and communication technology system." This report aims to provide a vision, goals, guiding principles, and 10 recommendations for the creation of the statewide system. The Commission's work is ongoing and future efforts are expected to focus on determining the feasibility, organizational structure, potential funding sources, and potential problems associated with the creation and maintenance of a statewide health information exchange.

Background

National, statewide and regional efforts are ongoing across the U.S. to develop forms of health information exchanges (HIEs). The purpose of a HIE is to provide an electronic means of sharing clinical patient information between healthcare entities which may include but are not limited to: healthcare providers, payers, pharmacies, laboratories, radiology centers, and public health departments. The development of a HIE is projected to have a significant positive impact on the quality of patient care, patient safety, and a reduction in medical errors and duplicative healthcare services. There may also be a significant reduction in the cost to deliver healthcare due to the reduction in administrative costs and reduction in the duplication of services.

SB 566 enacted by the legislature in 2004 established the State's Medical Informatics Commission. The Secretary of Family and Social Services, Mitch Roob, has served as the chairman of the MIC. The 15-member commission includes the commissioner for the state department of health, the commissioner of insurance, and one or more representatives from the following groups: physicians, hospital administrators, insurer, a health maintenance organization, legal expertise in matters concerning privacy and security of health information, computer information technology, healthcare information technology, the business community, and the Indiana Minority Health Coalition.

The chairman convened a five-member working group in early April to engage stakeholder groups and develop draft recommendations to bring back to the larger Commission. The working group has participated in numerous conference calls discussing the development of a vision, guiding principles, obstacles, and concerns toward that vision; and has worked with stakeholders to develop draft recommendations. The working group has also solicited information and feedback from the following organizations and individuals:

- Indiana Hospital & Health Association
- Indiana State Medical Association
- Indiana Pharmacists Alliance
- Indiana Chapter of the Healthcare Information and Management Systems Society
- Michiana Health Information Network

- Bloomington E-Health Collaborative
- The Center for Behavioral Health

The MIC further refined the draft recommendations provided by the working group. The working group's efforts and the solicited feedback have been instrumental in developing the MIC recommendations for moving forward.

At this time, the MIC brings forth the following vision, goals, guiding principles, and recommendations for a statewide health information exchange system.

Vision

Indiana will develop a statewide healthcare information system in which all relevant clinical information about a patient is electronically accessible at the point of care.

Goals

- Improve patient outcomes and the health of our community through improved access to and use of information:
 - Reduction in medical errors leading to patient harm
 - Improved quality of clinical care provided
- Reduce total healthcare costs through reduction in redundancies, administrative waste, and improved quality.
- Increase patient knowledge and accountability.

Guiding Principles

- Efforts should be patient-centric.
- Appropriate protections should be in place to ensure patient privacy, confidentiality, and education.
- To realize the most value, information needs to be accessible at the point of care and needs to be integrated into the providers' workflow such that it is useable.
- Recognizing that most health care is local, a community-based approach with regional information exchanges should be encouraged.
- Over time, data should be shared among regional exchanges.
- The likelihood of success is increased by (1) keeping the barriers to entry (participation) very low; and by (2) ensuring there is intrinsic value to those providers participating.
- Focus on realizable goals in a two-year timeframe, keeping in mind the long-term vision.

Barriers and Concerns

There are a number of issues that have been identified by the MIC that will need to be addressed as part of the effort to create a statewide health information exchange system. Several of these barriers and concerns are the focus of the Commission's recommendations. The issues include:

- Interoperable standards
- Lack of data accuracy
- Conflicting incentives
- Sharing of competitive information
- Issue of medical markets that overlap border states
- Funding
- Privacy & Confidentiality (including HIPAA)
- Ownership of data
- Lack of IT adoption in small, especially rural, MD practices
- Stark Act

Interoperable Standards

One of the challenges in moving toward an electronic health information exchange is the ability for different systems to communicate with each other. This is a technological as well as a sociological issue. For example, a laboratory test could be coded differently by two clinical information systems which would prevent the sharing of the result between those two systems. Also, different practitioners and health systems may use different semantics for the same entity (i.e., acute myocardial infarction, heart attack, MI, AMI). To ensure that all information is available accurately about a patient, it is necessary to develop a standard set of codes to address these concerns. This is being done nationally, as the Health IT Standards Panel, through a contract with the Department of Health & Human Services, is tasked with creating national standards. Many of these needed standards are already developed and in use (such as HL7 and LOINC).

Lack of Data Accuracy

Another major concern is how to ensure that the information put into the system and pulled out from the system is accurate and associated with the appropriate patient. Patients are seen in multiple settings and by many different providers, each using distinct medical record numbers for identification. Also, patients may have different names or multiple names that have been used in different systems. The fear is that when trying to aggregate all the information about a single patient, important data will be left out, or the wrong information will be included leading to inappropriate medical decisions being made. To address this there is some support for a single patient identifier to be used. This has some significant drawbacks, including large administrative and cost burdens to set up such a system. There are also questions as to whether this would sufficiently address all the concerns about data accuracy. Without the single patient identifier, patients' information can be found using robust probabilistic algorithms with good success.

Conflicting Incentives

When moving toward electronic health records, there is a perceived and often real disincentive for providers to expend the financial resources to do so. It is thought that many of the savings from these systems will accrue to the payer and not to the provider, since most healthcare is reimbursed in a fee-for-service manner. While this is true to a large extent, and needs to be addressed, there are additional savings available through these systems, such as reduced transcription costs and storage of paper files. It would be helpful in the first respect to consider what value propositions would lead to increased provider uptake, and in the second respect encourage more education and communication to providers about the benefits of good clinical information systems. An answer to the first issue is pay for value/quality/performance programs. The previous recommendation to create an organizational leadership body can effectively educate and communicate opportunities with stakeholder groups, while the recommendation to align pay for value/quality/performance programs among payer groups will address the value proposition.

Sharing of Competitive Information

The fear of sharing information with competitors, such as two hospitals within the same community, inhibits the development of local exchanges. For these initiatives to be successful, it clearly needs to be done in a collaborative atmosphere. This requires good leadership, communication among participants, and a clear vision about what is being done and why. This can be facilitated by the creation of a state organizational body (Recommendation #2).

Issue of Medical Markets that Overlap Border States

Many of Indiana's medical markets, or natural referral regions, cross over into bordering states. As Indiana works toward our state vision, it will be necessary to be at least aware of what our neighboring states are doing, and likely to partner with them where appropriate to ensure effective sharing of information across borders and common policies where needed. The members that form the organizational body recommended previously are encouraged to engage relevant stakeholders in border states to assist in this effort.

Funding

While incentives and grants from state and federal government have been, and will continue to be, indispensable sources of funding for fledgling health information exchanges, it is widely assumed that HIEs must ultimately be self-sustaining. Therefore, business models must be devised that identify persistent funding sources that are sufficient to pay the costs of operating, maintaining, and advancing the state's health information exchange.

Privacy & Confidentiality (including HIPAA)

Several of the Commission's recommendations are aimed at addressing the need for appropriate security of patients' health data. These are defined below within the "Recommendations" section of this report. In addition to the public's sensitivity to this set of issues, state and federal laws such as the Health Insurance Portability and Accountability Act of 1996 (HIPAA) must be considered and addressed in the creation of a statewide HIE.

Ownership of Data

Another issue requiring legal investigation and clarity is the ownership of health data within the state of Indiana. What data is considered to be owned by the patient, versus the health-care provider or payer, and what circumstances establish ownership may have a bearing on how the exchange of information is architected, who must approve or authorize the exchange, and what rights individual patients have to control the use of data pertaining to their health.

Lack of IT Adoption in Small, Especially Rural, Physician Practices

It is believed that the lack of IT adoption, infrastructure, and know-how in smaller physician practices will represent a challenge to the implementation and use of a statewide health information exchange. This obstacle may be especially pronounced in rural areas where information technology infrastructure is less available.

Stark Act Regulations

The United States Department of Health and Human Services (HHS) has enacted regulations prohibiting physician self-referral and other anti-competitive issues within the healthcare system. These HHS guidelines are collectively referred to as Stark regulations. As Indiana moves forward with the development of a statewide information exchange, it will need to be aware of these regulations and design a system that operates within the bounds of Stark regulation. That being said, the federal government has recognized the benefits of healthcare information technology and has recently created exceptions to Stark prohibitions specifically designed to clear the way for collaboration between physician practices and other entities within the healthcare system to encourage the adoption of beneficial information technology.

Recommendations

As the core of this report, the Medical Informatics Commission has formulated 10 recommendations intended to guide future efforts to create a statewide health information exchange system. These recommendations and corresponding explanations comprise the remainder of this report.

Clinical Information Set

Recommendation #1 – This priority list of information should be shared with government leaders, and those initiating the development of health information exchanges to emphasize the information that will have the largest impact in the short-term.

To further define the details of the initiative, it is helpful to specifically list the types of information that would be useful to providers to achieve the vision and goals noted above. In evaluating each type of clinical information, the group created a matrix to determine the clinical utility (i.e., to what extent the data is critical to or will influence the decision making process) and the technical feasibility (i.e., in a two-year timeframe how challenging is it from a technical or financial perspective) of including the clinical information. This matrix was reviewed and scored by all workgroup members, as well as the stakeholder groups. This method led to a priority list of data, such that the information listed first is both very critical/useful to healthcare providers and its inclusion is realistic in the prescribed timeframe.

Priority List of Clinical Information

- ♦ Patient demographics
- ♦ Radiological reports
- ♦ Laboratory results
- ♦ Allergies
- ♦ Medication history list
- ♦ Hospital admission and discharge information
- ♦ Provider notes
 - Outpatient notes
 - History & physical information
- ♦ Radiological imaging
- ♦ Eligibility information
- ♦ Claims information

Organizational Structure

Recommendation #2 – To facilitate the development of a statewide health information exchange, a public-private corporation should be authorized by the Legislature and appointed by the Governor. The board of the corporation should be composed of stakeholders and those knowledgeable in health information exchange. The group should sunset after four years, absent legislative reauthorization.

There are ongoing community-led initiatives throughout the state focusing on the exchange of health information. The more prominent ones include the Indiana Health Information Exchange (IHIE), Michiana Health Information Network (MHIN), Bloomington E-Health Collaborative, and connectivity centering on Medical Informatics Engineering in Fort Wayne. The feedback from across the state demonstrates a strong preference to maintain the autonomy/independence of local initiatives, which are each unique and best suit the needs of the local participants. Additionally, it has been noted that for these efforts to succeed locally, a spirit of collaboration is required. The ability to more frequently and formally share lessons learned, ideas, best practices/procedures, and technical knowledge among these groups would help both to advance the existing initiatives and to spawn similar efforts in other communities. While there is uniqueness to each community, the vast majority of issues and challenges faced are common to each group and this forum for exchange will act to accelerate progress.

It has also been suggested that the state could benefit from an "organizational infrastructure" that would facilitate the development of a statewide interoperable information exchange (as noted previously, the recommended method for achieving this would be to support and develop the local efforts and then work to connect those community-based exchanges). Secondly, this organizational structure should be responsible for ongoing leadership, guidance, and maintenance of the effort. Examples of further responsibilities could include identifying and brokering funding opportunities, working with government to address regulatory or legislative hurdles, or providing technical assistance to local exchanges (such as creating standard data use agreements, and access policies).

Funding for Information Technology Infrastructure

Recommendation #3 – The State should allocate funding for infrastructure for start-up needs (such as fiber-optic cables, hardware, and software) through grants or tax-credits prioritized according to a strategic plan put forth by the body as created above.

One of the largest hurdles to overcome in reaching the vision is the cost associated with the hardware, software, bandwidth, and especially the "change costs" resulting from reduced productivity. Many providers are reluctant if not unable to expend the initial costs to acquire and implement information technology improvements. The data demonstrates that urban centers have a higher proportion of adoption compared with rural areas, and hospitals and larger groups practices are more likely to have electronic systems compared with small groups or individual practitioners. These factors suggest that different strategies are required depending on the community targeted for adoption.

There is a need for both initial seed funding, which may include infrastructure such as broadband Internet connections, computer hardware in doctors' offices, and software, as well as ongoing costs including maintenance and upgrades. The sources of funding will likely come from different sources. The start-up funds are often grants; however, it is recommended that the regional exchanges develop a business model that will allow them to become self-sustaining. This can be accomplished through user fees, for example. There is also a trend toward pay-for-value/quality/performance whereby the insurers are paying more for better quality care. To achieve improved outcomes, providers likely will find it helpful and necessary to adopt robust clinical information systems. Alternatively, payers could pay a premium or bonus payment to providers just for utilizing an EMR, prior to the demonstration of improved outcomes, or regardless of demonstrated quality gains.

"Pay-for-Value/Quality/Performance" Programs

Recommendation #4 – Medicaid is encouraged to work with other payers, including Medicare and private insurers in Indiana, to develop standard pay-for-value/quality/performance programs (with common outcome metrics) to create a stronger incentive for providers to evolve their practice and adopt EMR or participate in a HIE.

An emerging nationwide strategy to improve the quality of delivered healthcare while helping contain the associated costs are known by the monikers "pay-for-performance", "pay-for-value", or "pay-for-quality" programs. The concept behind these initiatives is that if healthcare providers (e.g., hospitals and physician practices) and healthcare payers (e.g., Medicaid and commercial health insurance companies) can agree to specific measures that represent quality healthcare, then the payers would give increased reimbursement to providers that met or exceeded these measures. Lending the support of Indiana Medicaid to an effort to standardize these programs across the state would remove barriers to participation and help make them more effective.

Privacy & Confidentiality (Four Related Recommendations)

Recommendation #5 – A standard policy should be set up about how information is accessed by these systems. A two-tiered policy is recommended, whereby standard health information is easily available to appropriate providers, but certain information such as HIV test results, or mental health notes are more secure and inaccessible unless a patient specifically requests that they be shared. These tiers will need to be defined, and could be done so by the statewide organization.

Recommendation #6 – Consider recommending some type of certification requirement for security features (e.g., encryption) of electronic health record products or HIE systems.

Recommendation #7 – Consider the appropriate timing and substance of a public education campaign to be conducted by the statewide body with state funding that effectively communicates the benefits, and works to alleviate the public concerns as noted.

Recommendation #8 – The Commission recommends against establishing a single patient identifier for the citizens of Indiana at this time.

The public perception of this as an issue cannot be underemphasized. There is a significant perceived concern about the safety and security of the sensitive health information that would be present in such systems. Some of these concerns include the consequences of an employer or insurer discovering sensitive health information on a patient that could lead to termination or reduction of health benefits; theft of personal identifying information such as social security numbers, date of birth, or credit card numbers; and public discovery of personal health information such as infectious diseases, mental health disorders, or addiction. While these issues are extremely concerning in theory, it has not been demonstrated that electronic systems are necessarily any less secure than paper filing cabinets in providers' offices. The public is likewise concerned about the cost and quality of their healthcare and in most cases would want their provider to have the necessary information at hand to make appropriate decisions in their care.

Ownership of Data

Recommendation #9 – Explore the ramifications of a policy that establishes the patient as the owner and controller of their health information.

There is some disagreement as to who owns the health information that would be necessary to include in the exchanges. Patients obviously feel that this data is their health information and is their legal property. The providers that order the tests and produce assessments on patients at times feel that the records should be under their control. Additionally, there is claims information that may be considered to be the property of insurance companies.

Recommendation #10 – Health information sharing should begin as soon as possible.

Given the potential benefits for the citizens and healthcare system in Indiana, the Commission recommends that health information exchange within and across the state should be achieved as soon as possible. Existing efforts should be supported and grown and a plan for creation of a health information exchange that encompasses the whole state should be created and pursued.